

GENDER EQUALITY PLAN

FONDAZIONE
Telethon



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INTRODUCTION

Gender Equality Plan

During the 2020 edition of the European Research and Innovation Days, Jean Eric Paquet, the European Commission's Director General for Research and Innovation, announced – among the provisions introduced to foster gender equality in European organizations – the call for adopting a Gender Equality Plan (GEP) for all research and higher education bodies as a requirement for access to funding from the Horizon Europe research programme. The measure is a part of the policies of the European Commission to promote gender equality in research and innovation, which goal has been identified for more than two decades now as among the priorities of European policies, featuring alongside similar measures already adopted, nationally, in various universities.

The European Commission's initiative is part of the 2020-2025 EU strategy for gender equality. The strategy's ambit includes goals and actions toward a gender-equal Europe, displaying significant progress by 2025. The main goals outlined by the Commission are:

- ending gender-based violence
- combatting sexist stereotypes
- closing the gender gap in the labour market
- addressing the wages and pensions gap
- achieving gender balance in decision-making processes.

Within the ambit of lines of financing under Horizon Europe, funds will be allocated for actions that sustain development of Gender Equality Plans in research and innovation. Specific funds will be set aside for gender studies and interdisciplinary research.

State of Commitment

- Fondazione Telethon ETS' values and activities, and their impact, are based on the Sustainable Development Goals set forth by the UN in the Agenda 2030, with particular reference to the goals relating to areas of research and access to care: #3 (Good health and well-being), #9 (Industry, innovation and infrastructure) and #17 (Partnership for the goals). In pursuing its mission, Fondazione Telethon ETS also contributes, albeit indirectly, to Goals 1 (No poverty), 4 (Quality education), 5 (Gender equality) and 10 (Reduced inequalities).
- Fondazione Telethon ETS is committed to protecting and promoting equality among people of all genders, and to preventing discrimination in all areas.
- Equality means that everyone should have the same opportunities, rights and duties regardless of gender.
- It is the policy of Fondazione Telethon ETS to promote equal opportunities and inclusion of all resources of the organization.
- Fondazione Telethon ETS is committed to having representatives of all genders in each Area and on each level of the professional ranking.
- Fondazione Telethon ETS is committed to fostering a sense of community and transparency, and is committed to pinpointing and combatting any form or practice that may create inequality.
- The Gender Equality Plan of Fondazione Telethon ETS, in line with national and European legislation, reconstructs the state of the art on gender equality and inclusion within this organization.
- The data collected in order to draw up this document are updated as of December 31, 2022, and will be monitored and revised, if necessary, on a yearly basis.
- This document can be accessed on Fondazione Telethon ETS' website: <https://www.telethon.it/en/about-us/our-foundation/>

Dedicated team

The work on this Gender Equality Plan sees the contribution of a working group, responsible for the plan's drafting, implementation and dissemination.

The team is made up of representatives from the *Direzione Risorse Umane e Organizzazione* (human resources and organization department), *Direzione Amministrazione e Finanza* (administration and finance department), *Direzione Ricerca e Sviluppo* (research and development department) and the two institutes, TIGEM and SR-TIGET:

- **Ilaria Penna, Welfare, Organizational Systems and Quality Manager:** she aims to ensure the well-being of employees at their workplaces, and to foster an appropriate work-life balance. She also ensures not only the monitoring, maintenance and development of processes with respect to quality but also health and safety issues at the Fondazione's workplaces.
- **Monica Saraceni, Selection, Training and Development Manager:** she manages employee selection, performance assessment, and training to enhance professional skills and capabilities.
- **Isabella De Dilectis, Grant Office Manager:** she manages and supervises the administrative procedures regarding internal grants. She also backs up the institutes at the applications stage for calls for bids. She coordinates negotiation, management and reporting relative to external competitive bidding.
- **Elena Bruno, Senior Manager & Quality Inspector:** she supports the Research and Development Department in the administrative management of all aspects linked to the peer review procedure.
- **Graciana Diez, Chief Scientific Officer of TIGEM:** she furthers scientific research by managing and supervising TIGEM's Core Grant, She also coordinates the *Ufficio Scientifico* (scientific office).
- **Renata Ponzè, Administration and Control Officer of SR-TIGET:** she oversees and manages all issues related to administrative, budget, monitoring and security aspects of Tiget, in collaboration with Fondazione Telethon ETS.

FONDAZIONE TELETHON ETS

About

Responding to a call from families and volunteers of the Italian Muscular Dystrophy Association, Telethon was established in 1990. The foundation's focus was then extended to take in all rare genetic diseases, in order to seek cures through scientific research. The identity of this organization has evolved over the years around the concept of cure provision – as a body thanks to which no-one should be left behind.

As of 30 March 2022, Fondazione Telethon possesses the status of Third Sector Entity (ETS) following inclusion in the national register of the Third Sector (RUNTS) as per the Third Sector Code (*Codice del Terzo Settore*) and Legislative Decree 117/2017.

Fondazione Telethon ETS is the first non-profit organization to take on the development and the commercialization of a gene therapy. For more than three decades, it has stressed the importance of diseases neglected by large investors, both public and private. It does so by developing diagnostic methods, drugs and tools to sustain quality of life. This effort is sustained by adopting a rigorous method of selection of the projects to be funded, with ISO 9001:2015 quality certification.

During 2023, Fondazione Telethon has achieved a great goal: the signing of the first collective agreement in Italy concerning the protection of researchers in the private but not industrial sector. The organization has engaged actively with the sociale parts, in order to enhance and to promote the work of researchers, going beyond atypical and precarious contracts, that unfortunately in Italy have always negatively characterized scientific professional careers.

Thanks to the donations of those who in recent years have chosen to support the Fondazione and its Mission, Telethon has made significant progress in understanding the mechanisms of many diseases, with significant knock-on effects on diagnostics and development of therapies,

taking us well beyond the sphere of rare diseases as such and with broad application potentials – from vaccines to oncological immunotherapy.

To date, therefore, the foundation has made considerable progress against rare genetic diseases, thanks to a collective project all players of which (researchers, volunteers, the patient community, and private and corporate donors) pull their own weight. Telethon also pursues this goal by teaming up with the pharmaceutical industry to ensure that science concretely impacts people's lives – all part and parcel of the Telethon's mission. Today, the successes achieved are the building blocks with which we shall continue to construct a future when it is no longer an irremediable misfortune to be born with a genetic disease. Since several urgent questions remain unanswered, this is a challenging goal, all the more so as time goes by.

Over the coming years, taking care of people who have rare genetic diseases will mean making sure the most advanced knowledge in genetics shall lead to ever quicker, ever more accurate diagnoses, so we can translate into new therapies our understanding of diseases that currently await cures, while safeguarding access to the treatments developed so far – for all patients who can benefit from them.

The lean structure of Fondazione Telethon ETS sees four organizational levels to ensure flexibility and speed in decision-making, as represented below:

- Management teams
- Areas
- Coordination
- Organizational units

We can briefly list the aims of each team as follows:

- **General Management**

Together with the Management Committee composed of the directors of functions (Human Resources and Organization, Administration and Finance, Fundraising, Research and Development), this team guides and directs the Organization

In the staff under the General Director we have the areas relating to external and institutional relations, responsible for representing the Fondazione nationally and internationally, managing relations and networking. Also forming part of General Management is the area that manages and fosters Relations with Patients' Associations. In addition to creating moments of sharing, listening and collaboration with associations, this area serves as beacon or point of reference for the entire Organization.

Reporting to the General Director is the Purchasing Manager, responsible for ensuring maximum transparency in Procurement of Goods and Services.

- **Management of Human Resources and Organization**

The activities of this area mainly regard development of working activities and of the quality of the working environment, in which actions are ethically guided, in line with the values of the Fondazione. The aims of this area therefore include enhancing the skills, motivation, and well-being of all resources, as well as ensuring proper contractual bargaining practices and management of administrative requirements impacting personnel. Adequate support and IT instrumentation is to be provided according to needs and work activities. In addition, the area includes the legal team whose responsibilities include handling purchasing contracts, testamentary bequests, and privacy.

- **Management of Administration and Finance**

This area deals with a great many aspects of the management of the operational and research structure: first and foremost, budget planning and compliance. Telethon has always considered transparency one of its operationally key concepts, as well as efficiency (a goal that the administration also pursues through costs analysis). Administration must manage the funding received from external sources with the utmost care and attention. It must ensure proper reporting.

- **Management of Fundraising**

This area fosters contacts with donors, and coordinates networks and volunteer initiatives in town and city streets and squares. Projects targeting corporate players and schools are delineated. Direct Dialogue (*Dialogo Diretto*) is developed nationwide. This area communicates the mission and the results of scientific research via social media, the website, videos, Telethon news (*Telethon Notizie*) and the mission report (*Bilancio di missione*). Fundraising also means the TV marathon broadcast on Rai channels (national State broadcaster), with all the organizational problems of such events.

- **Management of Research and Development**

The key objectives here are implementing contacts to foster industry partnerships and subsequent coordination of clinical development of Telethon therapies (in partnership with pharmaceutical industry players). These are the fundamental stepping stones to developing therapies to provide cures.

To this area belongs coordination of peer-review procedures, namely the method adopted to select and fund the most deserving projects, with the aim of exclusively encouraging research of excellence. The Research and Development management area is also responsible for monitoring the progress of research projects and for finding external grants, while turning extramural research to good account.

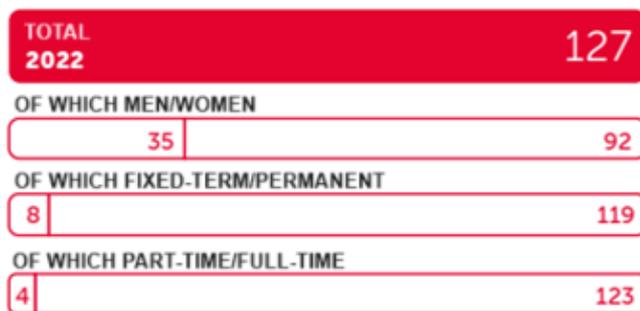
Data

As of 31 December 2022, the data on the structure of Fondazione Telethon ETS indicate a population totalling 139 resources (employees and collaborators), of whom 103 are women and 36 are men (**Graph 1**).

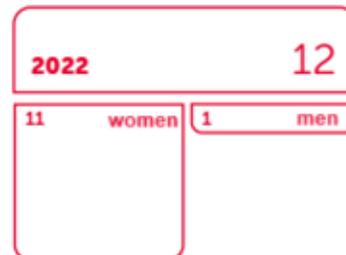
The working personnel breakdown aligns with the sector to which the organization belongs (non-profits). Indeed, 74% of this population self-identify as female (**Graph 2**).

Graph 1

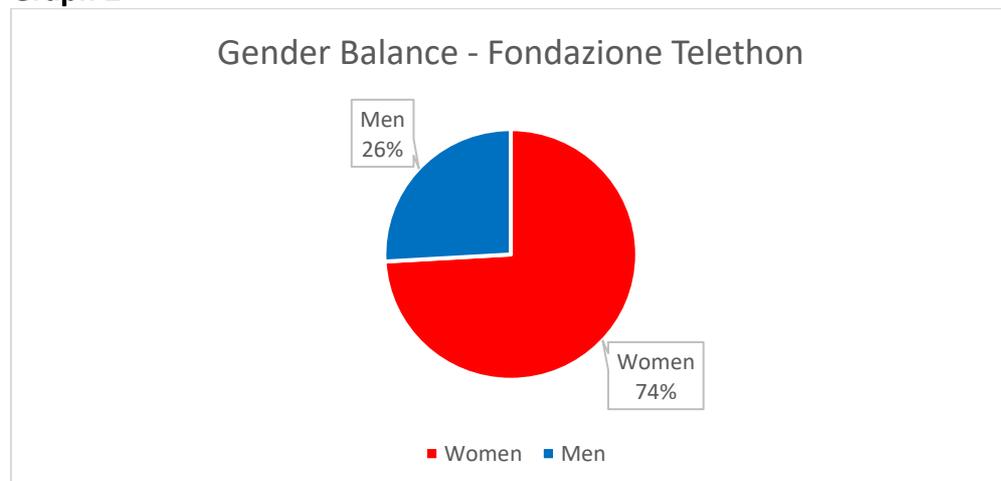
→ EMPLOYEES



→ COLLABORATORS



Graph 2



TIGEM

About

Headed by Professor Andrea Ballabio, the Telethon Institute of Genetics and Medicine (Tigem) is among the world's leading research centres in the field of genetic diseases. Since its inception in 1994, this centre has been at the cutting edge of genetics studies. The researchers working at the center – now housed in Pozzuoli on the site of the historic Olivetti factory – are committed to revealing the origins and underlying mechanisms of rare genetic diseases, in order to develop innovative therapies. Tigem has greatly contributed to developing early gene therapies for certain forms of hereditary blindness. The institute attracts researchers from all over the world, who contribute to maintaining its high level of competitiveness – as also confirmed by an ability to attract prestigious international funding (e.g. from the European Research Council (ERC)).

Tigem also plays a key role in next-generation genetic diagnostic applications.

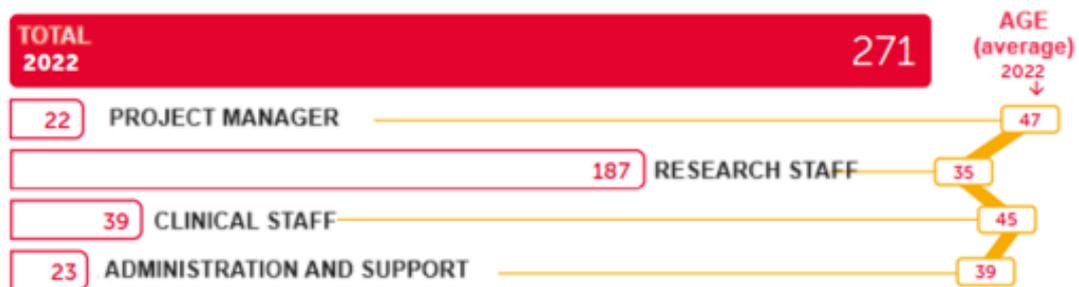
The institutional missions consist in shedding light on the origins of rare genetic diseases, and on the altered molecular mechanisms behind these, and in using this knowledge to develop innovative treatment strategies. Tigem therefore adopts a multidisciplinary approach that integrates the contributions of three research programmes. It thus addresses from diverse but complementary angles unresolved scientific questions. This approach enables Tigem's research to advance from basic studies on to translation studies and clinical trials.

Many diseases have been tackled, with the institute's particular focus on metabolic diseases (lysosomal storage diseases, flawed hepatic metabolism), diseases of the eye, and numerous diseases impacted by molecular processes (to the understanding of which Tigem has been a major contributor: e.g. autophagy and cellular disposal of toxic substances). These discoveries also impact the study of more common diseases, such as cancer and neurodegenerative conditions.

Data

The data for the institute, TIGEM, located in Pozzuoli (in the province of Naples), indicate an overall population of 271 resources. Again, women prevail among the personnel: on 31 December 2022, it represents 74% of this population as a whole (**Graph 3**).

Graph 3



→ FEMALE PRESENCE BY AREA (2022 data, % with respect to personnel)



SR-TIGET

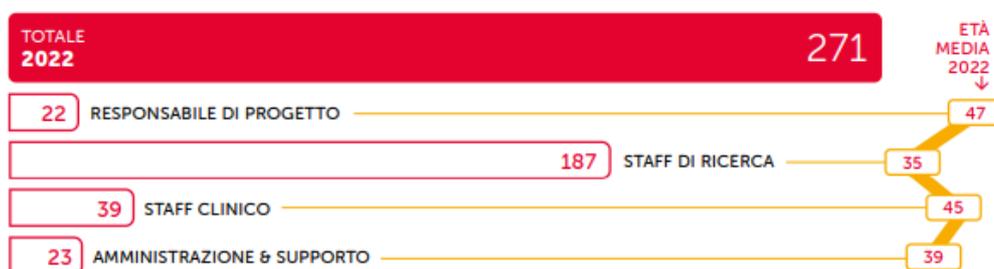
About

The San Raffaele Telethon Institute for Gene Therapy (SR-Tiget) is headed by Professor Luigi Naldini. It was founded in 1996 thanks to an agreement reached between Fondazione Telethon ETS and the San Raffaele Hospital in Milan. Indeed, this concrete integration of research and medicine (enabled by joining a major hospital) has led to the institute's becoming one of the world's leading gene therapy centres. SR-Tiget's research is credited with historic advances in the study of the early gene therapy approaches to immunodeficiency and development of a gene transfer technology platform based on lentiviral vectors, i.e. derived from HIV. SR-Tiget's contribution was vital for development of the world's first gene therapies to reach the clinical application stage. Two of these therapies – ex vivo gene therapy for ADA-SCID congenital immunodeficiency and ex vivo gene therapy for metachromatic leukodystrophy – have made it all the way through development and are available as drugs under the names of Strimvelis and Libmeldy. The institute's clinical unit is still the main hub for administration of these therapies in addition to therapies adopted experimentally as part of the clinical research programme. Patients from all over the world come to Milan each year to undergo these life-saving treatments. Therefore, alongside funding SR-Tiget's research programmes, Fondazione Telethon ETS has added a programme dedicated to assisting and supporting the families of patients involved in clinical activities, namely its 'as-at-home' (*Come a Casa*) hospitality project.

Data

The specific data as on 31 December 2022, regarding SR-TIGET in Milan, indicate an overall population of 271 workers among researchers, clinical staff, project managers and administration. The rate for women at the institute is above the average: 59% (**Graph 4**).

Graph 4



→ PRESENZA FEMMINILE IN SR-TIGET PER AREA (DATO 2022, IN % RISPETTO AL PERSONALE DI AREA)



WELFARE MEASURES

Fondazione Telethon ETS promotes and fosters the right balance between the professional and private lives of its resources. Drafting the Gender Equality Plan therefore entailed a mapping of Fondazione Telethon ETS' welfare measures (both mandatory as per Italian law and additional, in for over 12 years accordance with the proposals of the organization itself.

Measures foreseen by Italian laws

National law generally provides for measures that safeguard and further the interests of employees, occasionally also as set forth in contracts applying, as in the case of Fondazione Telethon ETS with *CCNL Commercio* national trade sector workers' contracts.

By way of illustration, the following is a partial list of the measures most frequently applied:

- **Mandatory maternity leave:** the organization augments the mandatory maternity leave compensation by the 20% cover not provided by Italy's social security system (*Istituto Nazionale della Previdenza Sociale, INPS*). It is therefore ensured that the female employees receive 100% of their compensation over their entire leave period (of 5 months).
- **Mandatory maternity leave:** as from 2022, fathers who are employees get up to 10 days' leave on the birth of a child. This leave period entails no loss in earnings (20% provided by the company and 80% by INPS).
- **Parental leave:** accorded to working mothers or fathers; it lasts a maximum of six months and it is refunded as follows: for the first months, 80% is paid for by INPS; for the remaining 5 months, 30% is paid for by INPS. According to the level of income and other features of the employee, since 2023 it is possible to request it even for a total of 9 months.

- **Child illness leave:** this leave is unpaid, but it is without ceiling until the child is three years old;
- **Law 104:** this law of 5 February 1992, no. 104 (generally known as Law 104) is a law of the Italian Republic that sets forth the principles governing rights, social inclusion and assistance in favour of the disabled. Law 104 is founded upon values such as elimination of causes of invalidity, a fostering of self-sufficiency and progress made toward social inclusion. This law grants three days' paid leave per month to workers with a handicap or to workers aiding a family member presenting with a handicap.
- **Sickness:** the first 3 days are fully compensated for by the employer, up to the second such period each year. Absences from day 4 to day 90 are compensated for (75%), Absences from day 91 to day 180 are also compensated for (100%).
- **Accidents:** the first 3 days are fully compensated for by the employer, days 2 to 4 are in part compensated for by the employer (60%). From day 5 on, compensation (60%) is received from the National Institute for Insurance against Accidents at Work (INAIL) day 90 (rising to 75% from day 91 on).
- **Part-Time:** according to part-time arrangements, the duration of work times is briefer than for standard full-time work times, as regulated by law (40 hours per week) or by the collectively bargained contract. Part-time arrangements may be horizontal (each day, but on fewer hours) or vertical (full time but for fewer days per week). At present, 7 female resources working for Fondazione Telethon ETS have opted for horizontal part-time work arrangements.

Additional Measures

Fondazione Telethon ETS wishes to provide a response to the needs of its own resources. With a view to fostering the right balance between work and the private lives of resources, it has decided to provide additional welfare measures, over and above those required by Italian law.

It also enhances professional skills and capabilities. To this end, the foundation adopts the values of meritocracy and continuing development.

2022-2024 Welfare project

Thanks to funding obtained from the Presidency of the Council of Ministers - Department for Family Policies, it was possible, under the public notice, *“Conciliamo”* (let us conciliate), to implement the project, WITH US (welfare investment in Telethon for healthy and useful support) (economic value: €842,684.00). The project (aimed at developing corporate welfare and favouring work-life balance) targets employees of Fondazione Telethon ETS and of TIGEM and SR-TIGET.

Specifically, the project consists of three actions:

1) Stabilization of women’s roles

In line with one of the objectives of the notice (increasing female employment), Fondazione Telethon ETS is committed to stabilizing female resources present in the organization and providing for new placements. This action aims to boost employment of women and to ensure actions for any prospective mothers in the organization.

Telethon is committed, in particular, to converting current fixed-term contracts/collaboration agreements with women into permanent contracts. The same aim also regards new permanent placements, to foster a stable, secure employment base

that will encourage and incentivize personal projects, this action furthering good family-friendly practices as a positive organizational element.

2) Psychology help-desk

This service is provided by way of response to the problems of Telethon employees and family members (psychological, individual, relational and/or work-related).

This service stems from thinking on the pandemic and Telethon's remote-working arrangements, the aims being to augment personal well-being (in view of this new approach to work and relationships), to change processes and to provide resources in need of this service with emotional support in their working lives.

For this service, the services of a qualified female psychologist have been made available to Telethon workers to provide psychological support on demand to all those who need it, aimed at balancing family life and work. The service will be activated at the help-desk via individual meetings (either face-to-face or remote), pending voluntary requests from workers.

3) Welfare platform

For all beneficiaries of the WITH US project, a welfare platform has been implemented plus individual vouchers loaded with the credit to be spent.

All beneficiaries can use their vouchers as set aside (via dedicated platform, web and personal account). Beneficiaries can browse the various services available, assess services available locally, and freely book the service required up to the ceiling for the values allocated.

Available services are specified by theme area:

- **Social security, supplementary healthcare and reimbursements:** supplementary contributions to social security funds, healthcare (for bodies or funds), education

and training (contributions for courses, and fees for children and for educationally extramural activities), season tickets for public transport services;

- **Work-life balance:** time-saving services (taxation and legal, delegated powers for red tape procedures), parenthood support (baby-sitting, toy libraries, summer and winter campuses), assistance for non-self-sufficient family members (home/residential social and health services, medical devices);
- **Health and wellbeing:** medical examinations, physiotherapy, psychological support, dietary advice;
- **Parenthood:** sustaining the activities of schoolchildren (revision, after-school, learning-disability support), university/educational guidance etc., parenting courses;
- **Training and personal and professional development:** counselling and coaching programme, training courses (technical and inter-disciplinary skills), language teaching;
- **Purchases and special agreements:** acquiring vouchers for products (18 goods classes available); more than 90 brands; price discounts (250 brands);
- **Leisure time:** travel and experiences (sports and catering), entertainment (cinema, theatre, museum, fairground tickets), sport and cures dedicated to hobbies.

‘Smart Working’ and flexible timetables

Fondazione Telethon ETS has decided to seize the opportunity to implement a broad-reaching policy of ‘smart working’, by introducing a new organizational way forward and by working on People, Spaces and Technology. Management and relationship dynamics stem from the ideals of a sense of responsibility, trust and team spirit.

Following on from the changes occasioned by the Covid-19 health emergency, Fondazione Telethon ETS decided to move towards an increasingly agile system oriented toward 'smart working', so as to better respond to new needs and changing working lives of all.

The current 'smart working' agreement undersigned by the employees of Fondazione Telethon ETS stipulates that 50% of the work should be done remotely. Indeed, employees also enjoy flexibility as to 'clocking in' and 'clocking out' by day and by week.

Holiday planning and company closure

Fondazione Telethon ETS assures all that it will announce via the company intranet, in a timely manner and in advance, its annual holidays plan, and indicate for the year in question the days of company closure, national holidays and patron saints' days for the various seats, and also any bonus days granted by the employer. This enables holiday planning in good time, benefitting personal and family life. For example, during the Christmas and Easter periods, company closures coincide with school closures, as is the case also for the timing of summer breaks.

Furthermore, from July to September, the staff at Fondazione can work to reduced hours each Friday.

Catering vouchers and special agreements

For all Fondazione Telethon ETS employees, the 'Ticket Restaurant' service is provided monthly for days worked, also remote-mode.

Special agreements stipulated by the Welfare & Logistics Area enable access to goods and services in the vicinity of the offices via special discount arrangements. Such arrangements include pharmacies, bars, restaurants, perfumeries, physical therapy sessions, opticians, hairdressers, hardware stores, supermarkets, newsstands and florists.

Children's party time!

Every year as schools close, Fondazione Telethon ETS, opens its doors to the sons and daughters of its resources. It organises a time of sharing and conviviality with its families, rounding off the day with a special surprise for all!

LOOKING AHEAD

Objectives for the future

Looking ahead, Fondazione Telethon ETS remains committed to raising awareness of gender equality and to fostering a view of inclusion. It also intends to promote and implement work-family life balance initiatives.

The interventions planned in this regard – addressed to the entire population of Fondazione Telethon ETS – are as follows:

- through meetings, providing information on contexts, both in general and specific, regarding gender stereotypes: how these stereotypes affect us, how we can be aware of them, and how we make sure that our choices and actions are not influenced by stereotypes;
- via the institutional website, informing our personnel of the updates of the GEP and the GEP's aims;
- by announcements, encouraging participation in awareness days (e.g. International Women's Day: 8 March; International Day of Women in Science: 11 February, etc.);
- Conducting an organizational wellness survey with the focus on work-life balance.

Final considerations.

Fondazione Telethon ETS has constantly ensured respect for genders and has favoured the work-life balance, especially considering that the overall percentage of the female population is far greater than for the male population: 70% of the total (a figure that leaves no room for further comment).

Indeed, for over 13 years there has been a woman at the helm of this foundation – Dr. Francesca Pasinelli. Overall, 56% of the managerial posts are held by women. This is a key fact that attests to gender equality within the organization.

Dr. Daniele Eleodori
Human Resources and Organization Manager
FONDAZIONE TELETHON ETS